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Link

mental health and intellectual and developmental disability...

coordinator's message...

Welcome to the latest edition of the School-Link newsletter.

Congratulations to all the schools who have taken part in our Group Stepping Stones Triple P parenting evaluation for 2013. We have 16 schools taking part and over 100 families. Most of the groups have completed the training sessions and have reported that the families have benefitted immensely from the program and from the support of their peers. I was fortunate enough to attend the graduation ceremony for parents attending the training at Beverly Park School (picture below), and chat to a few of the facilitators and parents, even the local mayor – who came along to hand out the parents certificates. It was so wonderful to see how valued the program is to the school and local community.

If any school or practitioner is interested in receiving Stepping Stones Triple P training, the University of Sydney is conducting a state-wide trial in 2014. The trial will begin with a state-wide survey called *My Say* in early 2014. If you would like to remain informed of any developments then please register your interest on our website www.schoollink.chw.edu.au/sstp-2014-elist/. We will then email you as we receive new information.

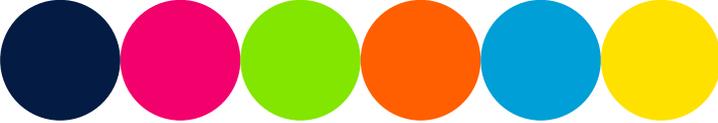
Congratulations are also in order to our regular editor Hebah Saleh who gave birth to a baby boy late June. She will be on maternity leave until next year. I will also be going on maternity leave at the end of August, returning March 2014. We will be employing a maternity locum shortly. The best contact email will be: schoollink@chw.edu.au.

Happy Reading. Jodie Caruana, School-Link Coordinator jodie.caruana@health.nsw.gov.au



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a note from David Dossetor...



Health Economics for Mental Health and Intellectual Disability: Evidence based medicine and the growth of health economics of preventative mental health intervention.

Associate Professor David Dossetor, Child Psychiatrist with a special interest in Intellectual Disability and Autism, Area Director for Mental Health, The Children's Hospital at Westmead.

Introduction

What has economics got to do with preventing mental health? In the current context where mental health is stigmatised and underfunded, I suspect that it will have greater impact than any advocacy or media event, and will do much more to bring agencies that deal with children together to transform the way we work to improve the prevention and treatment of their mental health. In the last part of the article I shall draw on what evidence there is for doing the same for children and adolescents with intellectual and other developmental disabilities. In short, health economics will provide the economic justification for up-scaling the national and international investment in mental health, as it will save and make money in the gross national product, at cheaper costs than other types of health intervention, let alone improve the quality of life and wellbeing in those at risk of mental disorder.

The development of mental health economics:

The first section of this paper is based on health economics research from the Personal Social Services Research Unit at the London School of Economics and Political Science in the United Kingdom (UK), under the leadership of Martin Knapp (Knapp,

McDaid and Parsonage, 2011). If the aim of mental health clinicians is the alleviation of symptoms, promotion of quality of life, support of family caregivers and improvement of broad life chances, this should also apply to those responsible for allocation of resources. However, resources are scarce relative to the demands and the needs of the population and choices need to be made, linked to the aim of the health system, to improve health and quality of life.

Economics brings a rational approach to managing scarce resources through cost-effectiveness analysis. In the mental health market economy, services are bought just like groceries but differences include: it is more difficult for the consumer to judge the quality of the service; consumers are unwilling to be seen buying services or as having mental health problems because of the stigma and prejudice (Knapp and McDaid). Further, the risks of consuming poor quality mental health services are greater than poor quality groceries. A mental health treatment can be expensive, often unaffordable, unless it is covered by a mental health insurance. Accordingly most middle to high income countries rely on prepayment systems such as taxation, or insurance which enables the benefits to be spread to poorer consumers.

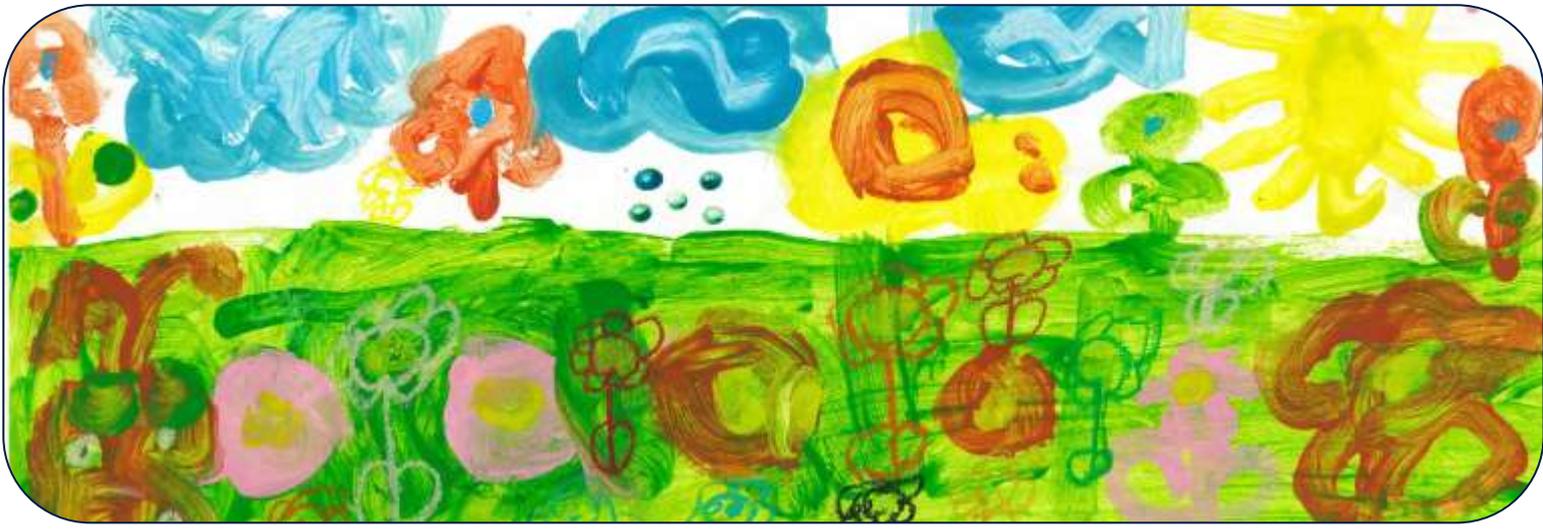
Consumers may also over use a free service. Accordingly, first world countries have a mix of public funding through taxes, or social insurance complemented by out-of-pocket expenses and voluntary private insurance. Demand grows with increasing numbers in contact with the services and those unrecognised and untreated identified through epidemiology. Resource limitation leads to the consideration of efficiency and equity of service provision. Choices include: Are a greater number of sessions delivered by a psychologist more or less efficient than fewer sessions delivered by a psychiatrist who also relies on the efficacy of medication?

Equitable allocation means giving more service to those with greater need, and charging poorer consumers less. The premise "Does it work and is it worth it?" is the basis of cost-effectiveness analysis. Cost-utility makes it possible to compare the costs between various health conditions. For example the cost of conduct disorder children was 18 times higher than other children, most noticeably including criminal justice systems costs.

"In short, health economics will...save and make money in the gross national product, let alone improve the quality of life and wellbeing in those at risk of mental disorder"

However only 5% of the cost benefit of parenting groups for children with persistent antisocial behaviours came to the health service, the rest fell to schools especially special education, social care agencies, families and welfare systems. It becomes a complex task to measure the cost or benefit because of the problems of costing across different agencies. For example children with persisting antisocial behaviour cost £5,960 per year, but cost of effective treatment was a one off cost of £4,307.

The trade-off of cost/benefit of treatment is measured by quality-adjusted life years (QALYs); this metric of how many people need to be treated for a particular condition with a certain treatment to gain one QALY enables a comparison between treating different conditions. In the UK, one QALY has been costed at £30,000 (\$46,000). For example QALYs show that the cost of improving depression by computerised cognitive behaviour therapy was cheaper than professional sessions. Conversely the cost of treating depression is mainly borne by health services but the cost of non treatment is borne mainly by unemployment, disability and welfare agencies. Such an economic analysis in the UK, led to £180 million increase in cognitive behaviour therapy services (CBT) **through the 'Improving Access to Psychological Therapies'.** For depression, one QALY by computerised CBT cost £1,250 pounds, by psychotherapy cost £6,412 pounds and by pharmacotherapy £16,138 pounds. Conversely, in severe depression medication is more effective and a recent adolescent study showed medication and specialised case management skills from a psychiatrist were cheaper than standard CBT from a psychologist. These are important considerations. In 15 to 24 year olds, 45% of all disability adjusted life years (DALYs, ie untreated QALYs) are due to neuropsychiatric disorders both in rich and poor countries, with accidents, self-injury and violence close behind. The rise of health economics research gives a rationale for improving population wellbeing and in consequence greater productivity and economic progress.



Knapp, McDaid and Parsonage (2011) have reviewed the literature for mental health promotion and mental illness prevention. They reviewed 15 topics based on availability of a significant body of research on these problems in the UK. The Odds Ratios (OR) of the benefit of these interventions only measure actual costs rather than the costs of QALYs, but an OR>1 has financial gain, for example an OR of 5 means for each £1 spent, other costs are reduced by £5! All examples are much cheaper than the average cost of a QALY in the general health system. Below is a selected number of topics applicable to mental health of children and young people.

1. Parenting interventions for the prevention of persistent conduct disorders (CD): CD occur in 4.9% of 5-10 year olds of which 50% persist. CD related crime costs £22.5 bn/ year and 1-2mn over the lifetime of a single prolific offender. Parenting programs to improve parenting style and relationships: improve 33% to no and 5% to moderate problems. Calculations listed over 25 years do not include benefits from improved employment, improved adult mental health outcomes and improved quality of life, and relationships. (OR 7.82)

2. Early detection of psychosis: Onset is in late adolescence-early adulthood. Early detection reduces the risk of transition to full psychosis and shortens duration of untreated psychosis. Intervention involves CBT, psychotropic medication and contact with psychiatrists, whereas routine treatment is provided by GP and counsellor. This increased costs in early intervention provision reduces subsequent health costs. (OR 10.27)

3. School-based interventions to reduce bullying: On average 39% of children are bullied in the previous 12 months. Adverse effects include psychological wellbeing, educational attainment, plus long term effects of employability and an aver-

age reduced lifetime earnings of £50,000. High quality programs with peer mediators and classroom intervention leads to a 21-24% reduction in the proportion bullied with associated benefits. (OR 14.35)

4. Early intervention (EI) for psychosis: 6900 young people experience first episode psychosis in England with high costs to public services. EI reduces relapse and readmission and improves return to employment, education or training and their future quality of life. Assertive treatment involves a multidisciplinary team and an aim of encouraging a return to vocation pursuits. EI cost less than standard care £10,927 to £16,704. (OR 14.35)

5. School-based social and emotional learning (SEL) programmes to prevent conduct problems (CD) in childhood: 6% of 5-10 year olds have severe CD (SCP) and 19% mild (MCP), rising to 9% and 29% in adolescence. Total crime cost of CD in UK is 60bn/year. Potential savings per SCP is £15000 and £7500 per MCP. Other costs include fewer qualifications, early age parenthood, unemployment, divorce, substance abuse, and psychiatric disorder. School-based SEL helps to recognise/manage emotions, set/achieve positive goals, appreciate the other's perspectives, establish and maintain relationships, make responsible decisions and handle interpersonal situations constructively. International research shows that SEL significantly improved social/emotional skills, behaviour, and academic performance at a reduction of 9% of both SCPs and MCPs. (OR 83.73, £132cost/family)

These interventions show extraordinary cost effectiveness. The most dramatic outcome was the Odds Ratio for Social Emotional Learning where the total returns for every £1 spent was 83.73 to 1, hence the title of this article 'a stitch in time saves... 84!'

Richard Williams, a Child Psychiatrist who was a guest at the RANZCP Child Faculty Scientific Meeting in 2012, has been advising the UK Government that with the economic recession there is greater necessity for investment in prevention as there will not be funding for adequate child and adolescent mental health services. In NSW there are significant intervention trials for some problems, including health visiting for post natal depression, parent training for conduct disorders (Triple P & 123Magic), early psychosis prevention and intervention (www.eppic.org.au), and preventing conduct disorder (CD) with social emotional learning ("getting on track in time").

The Impact of Schools on the Mental Health and Wellbeing of Children and Adolescents: The growing evidence.

NSW Department of Education and Communities recently commissioned "The psychological and emotional wellbeing needs of children and young people: models of effective practice in educational settings" (Urbis 2011). This extensive review of international literature found that over time students' wellbeing increased on a range of measures such as achieving developmental milestones, effective coping skills, positive attachments and positive social relationships. For example, the number of students who had experienced high psychological distress had reduced from 15.4% in 1996 to 13.3% in 2008. Yet students with both internalising and externalising mental health problems were also probably worse off. The report outlined an increase in the diagnosis of autism and other mental disorders, most common were ADHD (7%), social anxiety (4-9%), depression (4% in 13-17 year olds), suicidal ideation (20%) and CD (2% of 13-17 year olds). A high prevalence of bullying-including cyber bullying, an increase in numbers of young people drinking at concerning levels of alcohol and increased rates of obesity were reported. Other factors of concern were poor physi-

cal health including diabetes, body dissatisfaction and disordered eating, changes to families and family structures including increased sole parenting, heightened emphasis on achievement and disengagement from school of those unlikely to succeed (16%), rapid social and cultural change with materialism with individualistic values leading to alienation and social fragmentation.

The National Safe Schools Framework helps Australian schools to develop effective student safety and wellbeing policies. This national framework comprises of: 1. leadership commitment to a safe school, 2. supportive and connected school culture, 3. professional learning, 4. positive behaviour management, 5. engagement with the student with a focus on wellbeing and student ownership, 6. early intervention and targeted student support and 7. partnerships with families and communities. This framework has been further articulated in the MindMatters and KidsMatters Initiatives. Universal programs for student wellbeing and mental health are widely adopted including Social and Emotional Learning Programs (SEL) such as FRIENDS (developed in Australia), the Olweus Bullying Prevention Program and various cognitive behavioural programs, including services from school counsellors and psychologists. SEL models to respond to psychological and emotional wellbeing needs are more likely to be effective if they are: 1. aimed at promoting mental health than preventing mental illness; 2. involve the whole school and school environment, 3. promote adaptive, cognitive and behaviour strategies, 4. involve parents and the community, 5. take account of age and gender, 6. are implemented over extended time periods and allow for booster sessions 7. have positive presence of staff and mentoring. SEL also improves academic achievement (by 11-17 percentile points!), as well as stress management, empathy, problem solving,

and decision making skills (Durlak et al, 2011).

Selected programs are more effective than universal programs for students who are diagnosed or at risk for specific problems, even if universal programs promote protective factors and resilience. This may apply for students with depression, emotional disturbance, and violence. Timing and age of the students are important. Areas needing additional research include: where multiple ecological factors hinder delivery of programs, the development of social skills, when to refer to mental health services, disadvantaged groups including socio-economically disadvantaged communities, indigenous young people, same sex attracted young people, students from culturally and linguistically diverse backgrounds *and students with disabilities*.

“Social and emotional learning is most effective in primary school aged children and positive psychology for approaches for high schools...”

In summary mental health promotion is more effective than mental health prevention as a universal intervention. Social and emotional learning is most effective in primary school aged children and positive psychology approaches for high schools (HeadSpace National Youth Mental Health Foundation, 2011).

Selective school interventions for those identified or at risk of mental health problems

NSW MH-Kids commissioned an ‘evidence check’ from the Sax Institute entitled: ‘School based intervention programs and shared care collaborative models target-

ing the prevention of or early intervention in child and adolescent mental health **problems: a rapid review’ (2012)**. This focused on prevention and early interventions for various mental health problems including: anxiety, depression, substance abuse, CD (including oppositional defiant disorder), ADHD and eating disorders. The report examines, target ages, the types of interventions and describing examples of shared care collaborative models between schools and mental health services. This gives the reader an introduction to recognised programs.

The report classified school based mental health programs into six sub types from 1. awareness raising such as mental health first aid, 2. stigma reducing and help seeking, 3. SEL, 4. specific disorder prevention programs for selected classes or groups such as MOODGYM, 5. whole school programs such as Beyond Blue, Sensibility and Mind Matters, and 6. more intensive strategies for those students most affected by mental health.

However the review then focused on 4,5 and 6, thus providing a different slant from the Urbis review, searching both the black (peer reviewed literature especially randomised control trials) and grey literature (other unpublished reports such as PhDs and government and other agency’s reports). The optimal developmental age/stage for school based intervention or early intervention mental health program will depend on: age of onset of disorder (usually 2-3years before the average age of onset); risk factors and triggers associated with disorder, target groups more at risk, life transitions and stressors and availability of effective program for that age. A summary of specific disorders and programs are listed in table 1.

Health Auspiced Programs are where a mental health service has a relationship with schools, examples include: HeadSpace Australia, HeadStrong Jigsaw Ireland, Youth One Stop Shops NZ and NSW



Disorder	Affect	Recommended Programs
Anxiety	60% of 38 randomised control trials (RCTs) for anxiety prevention provided significant improvements and 74% of these were based on CBT.	FRIENDS (9-16years; Barrett et al, 2006); Stress Inoculation Training (15-17yrs; Hains & Szykowski, 1990); MoodGym (internet based, 13-17; Calear et al, 2009).
Depression	50% of 56 RCTs reported significant improvements of which 82% were based on CBT.	FRIENDS; Resourceful Adolescent Program (RAP) (13-14yrs; Shochet & Ham; 2004); Penn Resiliency Program (11-14yrs; Chaplin et al, 2006); Interpersonal Psychotherapy-Adolescent Skills Training (11-16; Young et al, 2006).
Substance Abuse	Successful universal alcohol interventions use a social influence approach eg resistance skills training with interactive sessions and improved environment. Effective drug prevention programs didn't focus on effects of drugs, or moral value driven approaches but exchange of ideas and developing new skills.	CLIMATE (used on-line resources) (13 yrs; Newton, Teesson et al, 2010); GateHouse (13 yrs; Patton, Bond et al, 2006); The School Health and Alcohol Harm Reduction Project (13 yrs; McBride, Farrington et al, 2004).
Externalising disorders	Multifaceted interventions eg with small group sessions and parenting programs eg Early Risers or Fasttrack or those that deliver single element based interventions. Eg Good Behaviour Game.	Good Behaviour Game (Grade 1; Barrish, Saunders & Wolfe, 1969); PeaceBuilders (Grade K-5; Embry et al, 1996); Responding in Peaceful and Positive Ways (Grade 6; Meyer et al, 2000).
Eating disorders	Body image dissatisfaction and attitudes to one's body have been improved with 'Everybody's different' stress reduction and self-esteem program (O'Dea & Abraham, 2000). Better outcomes involved programs that were interactive rather than passive, run by an expert rather than a staff member, that were multi-session programs, and incorporated dissonance induction or body acceptance content.	US Planet Health (females 10-14yrs; Gortmaker et al, 1999); Everybody's Different (11-14yrs; O'Dea, 1995); Media Smart (Grade 8; Wilksch & Wade, 2009).

Table 1: Summary of school-based intervention programs and shared care collaborative models targeting the prevention of or early intervention in child and adolescent mental health (Source: Sax Institute 2011).

School-Link Australia. There is not a strong published evidence of effectiveness. NSW School-Link Program began in 1999 when 8 Area Health Services were funded for mental health promotion prevention and early intervention (PPEI), Professional Training and Pathways to Care. The training in 10 topics are now available on DVDs. Evaluation found that school counsellors were more confident in managing less severe mental health problems (MHPs) and better at referring more severe MHPs.

Promotion, Prevention and Early Intervention (PPEI) for children and adolescents with intellectual disability and Special Education.

In 2009 Justice Health and the Children's Hospital at Westmead were also funded. CHW School-Link aims were reported in the needs analysis 'Leading The Way' (Dossetor et al, 2009) and the activities in advocacy, education, building path-

ways to care are well reported in editions of this Newsletter.

We have reviewed the literature on PPEI in children and adolescents with intellectual disability, of which there are few. **Feedback in 'Leading the Way' indicated that PPEI used in mainstream school settings are not suitable for those with intellectual disability.**

The programs found to be effective in schools that cater for intellectual disability are listed: those with some scientific evidence in bold (1-6) which are reviewed in Dossetor, White and Watson (2011), those that have encouraging findings (7-12). Research is usually restricted to mild intellectual disability but often the interventions are felt suitable for moderate intellectual disability.

- 1. Stop Think Do** (www.stophinkdo.com)
- 2. The Paths Curriculum** (www.prevention.psu.edu/projects/PATHS.html)

- 3. Social Decision Making** (www.footprint.com.au)
- 4. The Alert Program** (www.alertprogram.com/)
- 5. Stepping Stones Triple P** (www.triplep.net)
- 6. Emotion Based Social Skills Training** (www.ebsst.com.au)
7. Signposts (www.signposts.net.au/)
8. Secret Agent Society (www.sst-institute.net/)
9. Mindfulness/Acceptance and Commitment Therapy (www.actmindfully.com.au/)
10. Cool Kids (www.emotionalhealthclinic.com.au)
11. Problem based Learning (PBL) (www.pbis.org/)
12. Kids Matter (www.kidsmatter.edu.au/)

The Canberra Roundtable on Mental Health for people with intellectual disability on 22/5/13 emphasised the need to establish

both universal and targeted PPEI in schools. NSW Every Student Every School policy presents an opportunity for Special Schools to work together to build a range of curricula for promoting and preventing the mental health of children and adolescents with intellectual disability. KidsMatter and Positive Behaviour for Learning or Positive Behavioural Interventions and Support frameworks have evidence of benefit in mainstream schools but have been positively reported in special schools. They both represent whole school frameworks in which specific content is needed.

Kids Matter has four dimensions of activity: a positive school community, social and emotional learning, parenting support and education, and early interventions for students. PBL breaks school needs into universal/whole school proactive primary prevention (80-90%), secondary prevention for targeted or high risk groups (5-10%) and tertiary prevention for high need individuals (1-2%). Key elements are collaboration, data driven, educative, clear expectations of behaviour, and rewarding desired behaviours.

There are recent reviews on early intervention in Autism (and/or intellectual disability), which helps develop a framework for PPEI. For example Roberts and Prior (2006) identified the characteristics of effective programs and include:

1. Autism specific, with focus on attention, compliance, imitation, language & social skills;

2. Addresses needs for high support teaching environment;
3. Strategies to promote generalisation of new skills;
4. Addresses need for predictability and routine;
5. Functional communication approaches;
6. Support transition to preschool, high school and into post school/employment;
7. Family are supported and engaged in partnership with professionals.

“Improving the emotional and behavioural well-being of young people with intellectual disability is likely to have the greatest impact on reducing the cost of care....”

No intervention suits all, as different children respond in different ways. Early, intensive, family-based treatment programs have substantial short and long term benefits so long as adapted to the individual and family. Different interventions show great variation in cost of provision and no studies have looked at cost benefit.

A Framework for PPEI in special schools that cater for intellectual disability.

When considering all of the existing research and frameworks of mental health

prevention and promotion programs, the key elements applicable for most children with intellectual disability include:

1. **Specialised parent training programs** which show powerful effects and improve family relationships and attachments, despite the evidence that problems are often biologically driven. These could be part of admission to a special school, building a relationship with each family and their disability support team.

2. **Behavioural Approaches:** are widely used and have the second best level of evidence of effect in intellectual disability, which includes Applied Behavioural Analysis and Contingency Approaches.

3. **Development Promoting Programs** that are matched according to developmental stage are the next type of intervention which is widely accepted, and gradually establishing a scientific based (eg TEACCH):

a. **Augmented and Alternative Communication** for those with profound/severe intellectual disability and problems of motor and language development: motor skill development and sensory exploration are pre-requisites of programs that enable independent communication through such as with electronic devices/switches to express choice. This progresses onto object communication, followed by picture communication (White, Chapt 15 in Dossetor, White and Watson, 2011), but need to promote attention skills.

b. **Specialised Social and Emotional Learning:** Following the establishing some communication, next is programs that focus on the staged development of emotional recognition, followed by theory of mind and problem solving (such as EBSST) which are the components of specialised social and emotional learning. These are the skills that need scaffolding from supportive adults to facilitate internalisation of developmental competencies before social skills can be taught and children can develop relationships which in turn are the pre-requisite of mainstream SEL.

c. **Specialised Social skills Training:** Stop Think Do, The Paths Curriculum, Social Decision Making, The Alert Program are suitable SEL from an early stage, involving problem identification, identifying feelings and working out behaviours.

d. **Targeted intervention:** It is not clear whether targeted intervention such as Cool Kids and ACT/Mindfulness is also suitable as a universal intervention in special schools to improve anxiety and mood regulation or whether they are better reserved for high risk children (or suitable for both). There is a mental

Kids (with ID) Matter!

www.kidsmatter.edu.au

1. A positive school community

- Sense of belonging and inclusion by a welcoming and friendly environment.
- Collaborative sense of involvement of students, staff, parents, community.
- Examples, PBL or PBIS

2. Social & emotional learning for students

- Emotion Based Social Skills Training
- Stop Think Do
- The Paths Curriculum
- Social Decision Making
- The Alert Program

3. Parenting support & education

- Stepping Stones Triple P
- Other parent education sessions for e.g. that collaborate with disability or health services on communication or behaviour etc.

4. Early intervention for students experiencing mental health difficulties

- Cool Kids Child Anxiety Program ASD Adaption
- ACT Mindfulness

Kids Matter Framework adapted for intellectual disability

health promotion resource which has reported success in the United Kingdom with small groups of young adults with learning disability and we are looking at piloting this program in 2014 in a school environment with adolescents.

4. **Individualised Approaches** for complex cases require specialised assessment and approaches to intervention, although this can be in a classroom setting. Examples that have face validity but lack scientific evidence include:

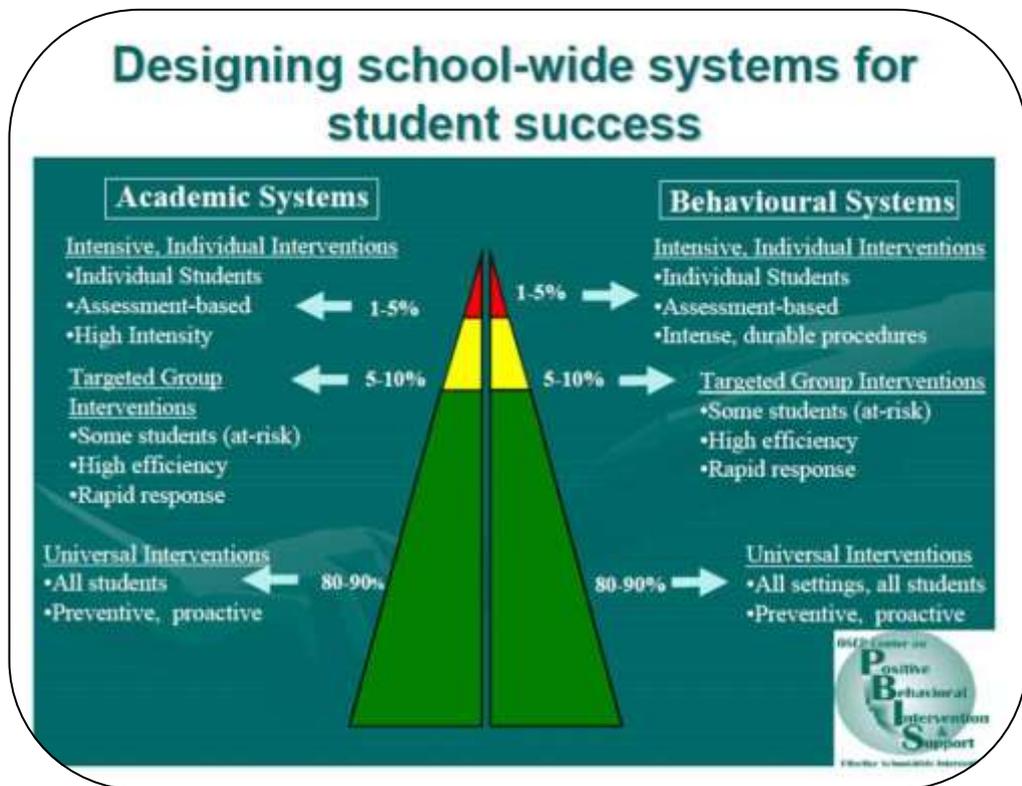
a. **Complex Learning and Developmental Disabilities (CLDD):** CLDD provides an individualised approach to understanding a child's problems with learning, taking a multidimensional approach using the Engagement Profile and Scale to help increase a learners' engagement leading to deep learning, modifying the learning process through dimensions of awareness, curiosity, investigation, discovery, anticipation, persistence and initiation, with a range of interventions. This model provides an interface between special education and neuropsychology, using educational approaches to understand and help (www.complexld.ssatrust.org.uk).

b. **SPICE Model** (Dosen, 2003): Social, Physical, Intelligence, Communication, Emotional are the dimensions of SPICE which are rated according to developmental age skills measured on each dimension. Jennie Curran (personal communication) has used this measure as an assessment tool to help design interventions for the mental needs of children and adolescents with intellectual disability and mental health problems, and are now using it in a special school-based project.

c. **Multidisciplinary School-based Clinics:** are being established in NSW in a number of Special Schools which are appreciated, but need evaluation. This can bring together the expertise of a specialist multidisciplinary team from disability, health and non-government organisations which can include: a paediatrician, an occupational therapist, a speech therapist, clinical psychologist and psychiatrist and family/cybernetics therapist. This diversity of professionals brings a range of skills which school staff can apply to both the presenting case and future cases including the management of high risk behaviour.

Conclusion

Health economics are likely to have a large effect in promoting and preventing mental health. In young people with intellectual disability, emotional and behavioural disturbance accounts for the greatest variance in the burden of care. Improving the emotional and behavioural well-being of



young people with intellectual disability is likely to have the greatest impact on reducing the cost of care. School-based PPEI is an important component to the lifespan approach to improving mental health in people with intellectual disability. Since there are large community costs in caring for people with intellectual disability it is pretty safe to predict that improved activity and skill in promotion and prevention of mental health is likely to be enormously cost effective, while also contributing to gain in quality of life and participation. This framework may be the basis on which special schools could test out interventions and add to the evidence on best educational practice and establish the health economic case for this special need population. CHW School-link would welcome further discussion or even a network of interested parties and partners on this topic.

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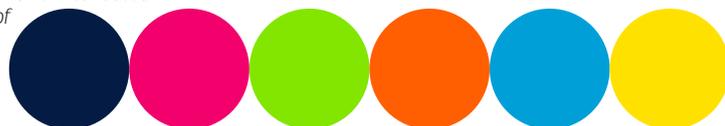
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Conference Reviews: Orange conference...

Cathie Matthews
School Link Coordinator & Speech
Pathologist
Western NSW Local Health Network

“Celebrating Diversity, Moving Forward Together”, was the theme for this year’s Special Education Conference held in Orange on 29th April 2013, and proved to be very popular with approximately 280 staff attending from the Western Education Region of NSW. The conference proved so popular again, that places filled quickly. The conference appealed to a range of Special Educators, School Counsellors, Support Learning Officers and Teachers across the Western region.

We started the day with the Key note speaker, Brian Smyth King the Executive Director, Learning and Engagement, NSW Department of Education and Communities (DEC). He provided an interesting keynote, **“Personalising learning and support to respond to student diversity”, consistent with the conference theme.**

Participants enjoyed 3 different workshops with a choice of 15 different sessions. **Some workshops were ‘sold out’ before the conference began.** Workshops included a broad range of topics including some very

interesting and practical sessions such as:

- Behaviour and Mental Health
- Headstrong; The Creative Way of thinking, talking and teaching about mood disorders, mental health and resilience.
- Sometimes the classroom hurts- Investigating the sensory environment.
- Risk Management; Re-thinking escalation and crisis in a school context.
- Positive Psychology in the Classroom.
- Community Engagement and Kinship Systems in Aboriginal Communities.
- Grief and Loss for Children
- KidsMatter
- The Australian Curriculum Life Skills and Builder program.
- Adjustments for students.
- Personalising your 21st century.
- Disability Legislation.

We were very fortunate to have fantastic local guest speakers attend the conference, as well as speakers from the Black Dog Institute, Redbank School, ADHC State wide Behaviour Intervention Service,

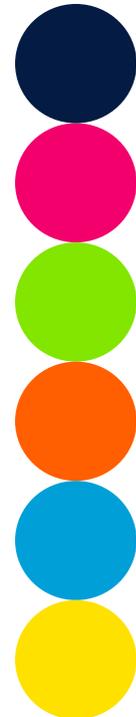
KidsMatter, Rural & remote Distance Education Unit. Participants enjoyed the opportunity to catch up and network with colleagues during the breaks and browse the range of trade displays available. Displays were available from services and programs such as the National Disability Services, Friends, Headspace, Kidsmatter, Child & Adolescent Mental Health, School-Link (local and CHW), and so on.

The highlight for many at the conference was the final, very insightful keynote address from a young student, and his father. TJ has high functioning autism and has experienced a range of educational settings. **TJ’s dad advocates effectively for so many children with autism, their parents and carers in the area.** TJ provided a very insightful and articulate presentation about his experiences at school, and strategies he has found helpful. He so confidently and honestly spoke about his experiences and responded to many comments and questions from the audience.

Access to a number of the presentations is available at: <http://rde.nsw.edu.au/celebrating-diversity>



Helping Families Change Conference...



Jodie Caruana
School Link Coordinator
Children's Hospital at Westmead

The 15th annual international Helping families Change Conference (HFCC) was held on 13-15 February 2013 in Los Angeles, hosted by Triple P International.

During the pre-conference workshops I discovered the latest Triple P parenting innovation: online and community Triple P. Local facilitators recruit families, provide online monitoring and feedback on completed activities. There is the regular online version for individuals and the second **online version is the "Triple P Community"** where a group of families start the online interactive education sessions at the same point in time and use a social networking approach to replicate the success of the group process. According to their research, Triple P suggest that online learning is favoured (second to mass media such a TV) by parents as they are increasingly accessing information over the internet including smart phones and tablets. An online version of Stepping Stones Triple P is currently being trialled in a national evaluation.

The conference opened my eyes to other versions of Triple P that are available or are in research stages, including: Resilience Triple P, Triple P for indigenous parents, Fear-less Triple P for anxiety in children and their parents; Disaster Recovery Triple P, Preparing for Bad Weather Triple P, Grandparent Triple P, and Baby Triple P.

The most notable key note address was from James Garbarino from Loyola University, Chicago and author of the Lost Boys. His talk on the challenge of parenting in a socially toxic environment was enlightening. He discussed that it is not only the parenting strategies used but where they decide to live, where they send their children to school, how much violence they are exposed and have access to that impacts on **a child's development and behaviour.**

Garbarino argued that in his opinion, high schools should not exceed 500 students in order to create a nurturing environment. He reported that the average high school size in the USA comprised of 1200 students. His main argument for large schools being a toxic environment has to do with opportunities to participate: for example in sporting teams, music clubs, parent involvement etc, simply because of the numbers of other students they would be competing for participation in these other areas.

Before his talk was even over I found myself googling statistics for Australia. According to the Australian Bureau of Statis-



Triple P Founder Professor Matt Sanders and School-Link Coordinator, Jodie Caruana

tics, in 2011, the average secondary school enrolments were just over 500, including 195 schools with over 1200 students. Primary schools were considerably lower with an average of between 200-300 students. Garbarino in his Lost Boys summary paper (2005) discusses the accumulation of opportunity as an **individual's developmental assets and describes** how schools can contribute up to 10 of these (with a maximum of personal assets being around 40), based on research from the Search Institute in Minnesota. This concurred with my own personal experience of attending a larger high school, and then attending a smaller one. How does this impact students with developmental or intellectual disabilities? Most schools for specific purposes tend to be

under 100 students in size anyway, however we need to ensure that in larger mainstream schools, there are opportunities for success and participation in academic and non-academic activities and for parental involvement not just for a select few, but for all students both with and without disabilities to enable the student to thrive.

Selected presentations from the conference are available on the HFCC website (including our School-Link evaluation on Group Stepping Stones in a Special School Environment): <http://helpingfamilieschange.org/about-the-hfcc/past-conferences/2013-los-angeles/>.

The 2014 international HFCC conference is being hosted in Sydney from February 19-21 2014. Further information is available at: <http://helpingfamilieschange.org/>

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Australian Bureau of Statistics (2011) 2011 Schools Australia 4221.0. www.abs.gov.au

Garbarino, J (2005) Lost boys: Why our sons turn violent and how we can save them. *In Paediatric Child Health* Vol 10 No 8 October 2005.

“we need to ensure that in larger mainstream schools, there are opportunities for success and participation ”



Getting students ready for life after school: Part 2...



Getting Students Ready For Life After School, Part 2: Post school education, training and employment options

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The Western Sydney National Disability Coordination Officer Program (WSNDCO) is funded by the Australian Government and works to improve the transition and participation of people with disabilities (including chronic medical conditions and mental health conditions) into post-school education, training and employment. WSNDCO is hosted by the University of Western Sydney Equity and Diversity Unit. There are 31 NDCO regions across Australia. To find an NDCO in your area, go to www.innovation.gov.au/ndco. You can find out more about the WSNDCO Program and access a large range of information and resources in the areas of education, training and work at www.uws.edu.au/ndco.

Last newsletter our article outlined the 10 top tips for schools and services. This edition we introduce the further education, training and employment options available after school and the types of supports available for each one. Which options are relevant or realistic for a young person will depend on a range of things, including their interests and skills and the type and severity of their disability. But it is important for a young person and their family to consider and find out about the full range of options so that they can make a well informed decision.

Things are very different to when most of us left school, and there are now a huge range of options available to young people with disability. This includes a range of support to assist people with disability to participate in mainstream courses and workplaces, as well as a range of disability specific programs and employment options. Below is a quick summary of the main options and some useful links. You can find much more information on our website www.uws.edu.au/ndco.

Ageing Disability and Home Care – Post school programs

Ageing, Disability and Home Care, part of the NSW Government Department of Family and Community Services, funds organisations to provide two post school programs for school leavers with disability: Transition to Work and Community Participation.

Transition to Work – is a two year program for young people with disability who need support to make the transition from school to work or further education. It helps young people develop independence, gain practical work experience and develop skills needed for employment or study. See http://www.adhc.nsw.gov.au/sp/delivering_disability_services/post_schools_programs/transition_to_work

Community Participation – is a program for young people with moderate to high support needs who may require an alternative to paid employment in the long term. It focuses on building independence, skill development and participation in the community. There are three different models for this program, including centre-based, community-based, and a self-managed model where young people and their family

organise their own activities and prepare plans for what they would like to do and how they will use their funding. See http://www.adhc.nsw.gov.au/sp/delivering_disability_services/post_schools_programs/community_participation

Access to both of these programs requires an assessment to be conducted during year 12 at school to determine eligibility.

TAFE

TAFE NSW offers a wide range of nationally recognised courses in many vocational areas and at various levels. TAFE also offers a range of flexible learning options including part-time courses, evening courses and distance or online learning. All TAFE colleges have specialist teacher/consultants (TCs) who provide support and adjustments for students with disability. Support offered includes assistance with course selection, assessment modifications, exam provisions, note-taking, access to assistive technology, and tutorial support, depending on the needs of the student. See www.tafensw.edu.au/services/disability/

University

All universities have disability services staff who are responsible for providing reasonable adjustments for students with disability. Upon registering with this service and providing appropriate documentation, a young person may receive support including assessment and exam adjustments, access to equipment or assistive technology, advice and advocacy. It is important to remember that even if a young person does not get into university based on their Australian Tertiary Admission Rank (ATAR), there are many alternative entry pathways that may assist them gain entry to university. See our Get Ready for Uni website

www.uws.edu.au/ndco/getready for more information or http://www.adcet.edu.au/Student_Resources/Who_Can_Help/University_Disability_Advisers.chpx for links to disability services at individual universities.

Other further education and training options

There are a range of other further education and training options. These include Adult and Community Education, such as local Community Colleges, and Registered Training Organisations. They may offer a range of benefits including flexible learning options and small class sizes. However it is important to be aware that most smaller training providers will not have a specific disability service in place. *All training providers are required by law to provide reasonable adjustments to students with disability, however a young person may need to negotiate and advocate for these directly with their teacher.*

Apprenticeships and Traineeships

Australian Apprenticeships (including both apprenticeships and traineeships) are available in a huge range of career areas and levels. They can be a great way to “earn while you learn” and combine the benefits of structured learning with on the job training. Australian Apprentices with disability may be able to access tutorial and mentoring support during their coursework, and workplace modifications through the Employment Assistance Fund. Their employer may also be eligible for wage incentives through the Disabled Australian Apprentice Wage Support Scheme. In many instances, starting an Australian Apprenticeship may be option while the young person is still at school. See www.australianapprenticeships.gov.au

Open or self employment

It may also be an option to seek a job in the open labour market, or for the young person to set up their own business. There is support available to do both of these things. It is important to be aware that it is illegal for an employer to discriminate against an employee or potential employee on the basis of disability. A young person is entitled to *reasonable adjustments* in the workplace, so long as those adjustments do not cause the employer *unjustifiable hardship*. The Employment Assistance Fund can assist with workplace modifications, equipment and other support a young person may need to participate successfully at work. There is a range of specialist assistance available to find and/or maintain open employment, for example Disability Employment Services and Job Services Australia. There is also a New Enterprise Incentive Scheme to assist eligible people to start their own small busi-

“It is important to keep an open mind during early transition planning and facilitate the young person to explore a wide range of possibilities...”

ness. Centrelink can help you access these and other employment services. www.jobaccess.gov.au is also a great resource for information and advice about disability at work.

Supported employment – Australian Disability Enterprises

If a young person is likely to require ongoing support at work, they may wish to consider an Australian Disability Enterprise (ADE). These are supported workplaces for people with moderate to severe disability. ADEs are commercial businesses which perform a range of services, including packaging, assembly, production, garden maintenance and landscaping, cleaning and laundry services. Employees are paid a productivity based wage for their work, which means that they are paid a portion of the full wage based on their level of productivity, usually in addition to a Disability Support Pension. ADEs can be a great way to learn new skills and develop the confidence to later move into open employment. See <http://www.fahcsia.gov.au/our-responsibilities/>

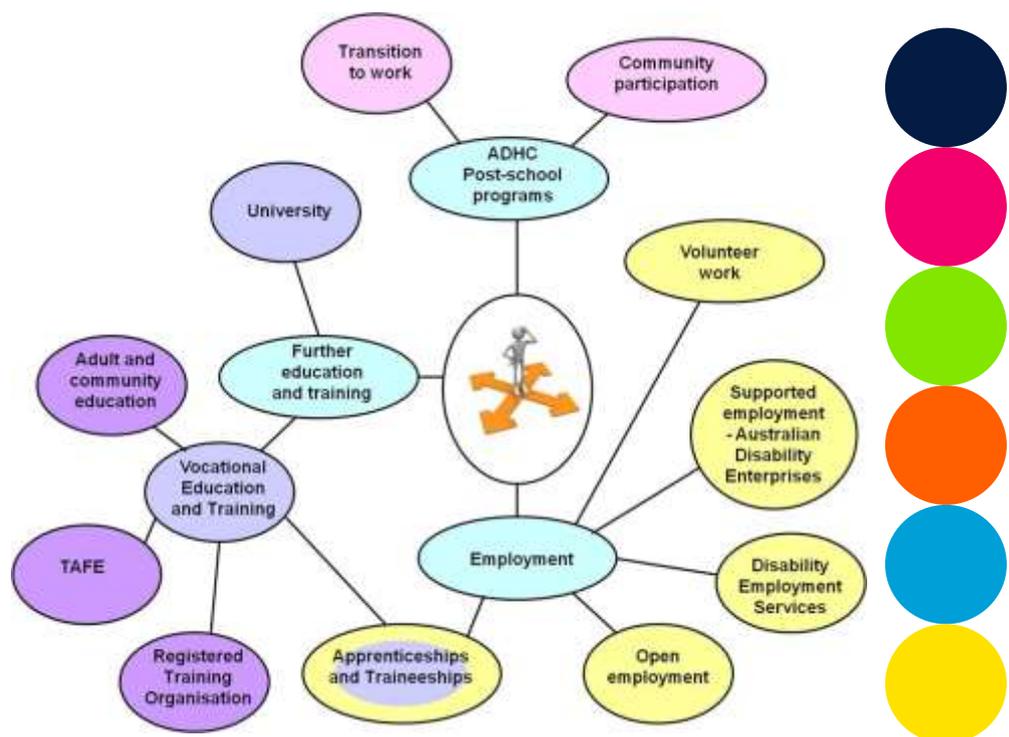
[disability-and-carers/program-services/for-service-providers/australian-disability-enterprises](http://www.uws.edu.au/ndco/getready)

Volunteer work

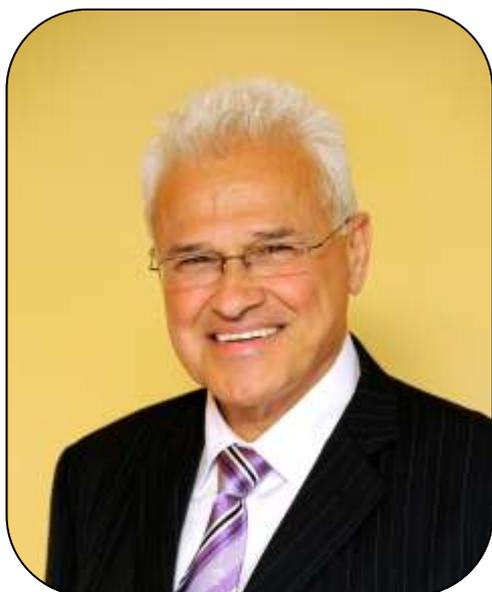
Volunteer work could be a great way for a young person with disability to: build confidence; develop skills; explore different types of work to see which career they would like to pursue; and identify the types of support or adjustments they may need at work. It is also a great way for them to give back to the community and contribute to issues they are passionate about. It can also lead to paid work! See <http://www.govolunteer.com.au/> for opportunities.

It is important to keep an open mind during early transition planning and facilitate the young person to explore a wide range of possibilities. With support, reasonable adjustments and/or access to assistive technologies, a young person with disability may be able to participate in options that may not initially look very feasible. By exploring a range of possibilities, you are facilitating the young person making a realistic, informed decision about the best pathway for them. Here is a visual summary to graphically illustrate these broad categories of post-school options:

You can find much more detailed information and advice on our website www.uws.edu.au/ndco. You can also download copies of our comprehensive workbooks and guides for young people and parents from www.uws.edu.au/ndco/getreadyoptips. We'd love to hear from you with feedback on any of our resources!



An Interview with Les White..



Les White is the inaugural Chief Paediatrician, NSW Kids and Families

You have had a very impressive career: Paediatric Oncologist, Professor of Paediatrics, Chief executive of Sydney Children's Hospital and now the NSW Chief Paediatrician: Has this been what you planned or hoped of your career?

I didn't have a specific roadmap when I started and I couldn't have predicted exactly where I would end up. Some of these positions arose along the way, such as the inaugural Sydney Children's Hospital executive position, which came as the hospital separated from the broader campus at the Prince of Wales, Randwick and the NSW Chief Paediatrician role which came out of the Garling enquiry. Broadly, I did have a desire to make a difference, so when the opportunity arose to do so at a broader system-wide level I took it up and went from there.

What has influenced your career most?

There are some individuals who have influenced my career in terms of role models. Most importantly, I have learnt that the health and wellbeing of children is a key component of what is good for all of society, for everybody. If children are healthy and well then all of society will benefit. This central theme is what got me interested in doing paediatrics in the first place and all the stages thereafter followed from there.

Do you still keep an interest in any areas of research?

Yes I do. Research has been an interesting evolution because I spent a lot of time on cancer research, both clinical and in the laboratory. I had a whole series of papers published and was awarded a Doctorate of Science for my contributions to

literature. Not surprisingly, my cancer work and research has tapered off over the last decade or so and my involvement with that is limited now with only one clinic a month. At the same time, I have become very interested in health services research and organisational culture research and I have transferred skills from one domain to the other. Although quite different there are nevertheless some transferrable learnings about the discipline of research and thinking in an enquiring way about the things around you. I find research very **stimulating and I wouldn't want to give it up**. At the moment I am looking at establishing a state-wide collaborative around studying the services for children as a major agenda for research.

How much do you feel that paediatrics is changing or has changed, say in the last 15 years?

There are huge improvements. First of all, the capacity to treat illness is far better. There are massive improvements in addressing acute illness or, indeed, acute presentations of chronic illness and many hospitalisations have been dramatically reduced as a consequence. As a parallel to that, while we treat and manage better **we don't necessarily cure so we now have** a rising burden of chronic complex disorders which is ongoing, beyond childhood into adulthood. So that is one major change and challenge, particularly when you add the transition to adult care context.

Another aspect of change is the increasing recognition of the continuities between child and adult health and wellbeing and the particular importance of early childhood. This looks not so much at the illness context but at overall wellbeing and becoming productive contributors to society generally. If you look at child health and wellbeing more broadly, evidence increasingly points to the impact it has on societal wellbeing as a whole. The scope of child health and wellbeing starts in-utero and continues right into young adulthood. We need to think much more broadly and recognise opportunities to make a difference early in this life-course.

What is your vision for paediatrics in Australia?

This is such a big question. Firstly, I would like to have these connections integrated into the way we work, from the impact of early childhood influences right through to young adulthood and all the transitions between. This broader view of child health and wellbeing also recognises the importance of the social determinants of

health and how they intersect with healthcare. If you are talking nationally, I would very much like the learnings from one jurisdiction to be translated into another so we benefit from each other's experience. This is not to stifle innovation, as there are always new initiatives in any jurisdiction or individual service, but the idea would be that we are very closely networked across the country so if something good happens in one area it is picked up in another fairly quickly.

To express this as coherent theme, I would like to see integration happening in multiple domains across not only the life-course continuum but also across the various dimensions of the service continuum. The latter includes: the tiers of service, often referred to as primary, secondary, tertiary and quaternary; the geographic and demographic divides; and the jurisdictional barriers. Progress in those four facets of integration to me would be a great achievement.

“If children are healthy and well then all of society will benefit.”

As co-chair of the ACI Disability Network, what are your interests in the health of people with an intellectual disability?

I was bought into that network partly because of my perceived capacity to facilitate and lead. I had no specific professional experience in intellectual disability. There is also a personal aspect of being a parent of a young adult with an intellectual disability. The network has lots of different players from various different perspectives and they needed someone who **didn't have a historic link with any one group**, who was independent and had the capacity to bring people together. I have ended up staying on longer than I had anticipated because it is such an important opportunity to make a difference.

What do you think the ACI Disability Network may be able to achieve to contribute to their wellbeing?

I was pleased to see in the last School-Link newsletter the outline of the ACI network and its structure and the various agenda items and subcommittees. The structure is designed to address a whole range of issues within the health system

and beyond. So it is very comprehensive. We have projects that work on cohesion and integration of services and others focus on making the patient journey as appropriate as possible. It is expected that over time the network may also be able to grow and enhance services, but we have to make sure that we know exactly what the best models are and how to progress them. In that domain there are also major opportunities to be part of the bigger picture, namely DisabilityCare Australia (NDIS) and the various state alliances that go with that.

How much do you think the DisabilityCare Australia (NDIS) will change things for people with an intellectual disability?

It is hard to know, but the optimist in me sees a whole new way of addressing needs. The fact that it has received the recognition and the profile that it has within the last few weeks, is in itself a huge achievement. People are now more aware that there are enormous challenges for both individuals with disabilities and their carers. The additional resources is a big component but with that goes a philosophical approach to maximising choice, supporting carers, trying to recognise the potential of people with a disability and to offer them maximum opportunity to develop their potential. So I do feel that there are some real major opportunities ahead of us and the ideal would be to be there at the forefront and to participate in the evolution of DisabilityCare Australia.

How much will that help health and mental health issues?

We know that people with intellectual disabilities have a much higher disease burden across the board: physical and mental. The mental health challenge is a particularly major issue. Sometimes I think of it as a triple whammy, as you may have physical disability or illness, intellectual disability and mental health challenges all happening simultaneously, which is a very tough combination. We need to use the opportunity of increasing awareness to put that squarely on the agenda and to keep working on it. It is one of the key aspects of what the ACI network and the various subcommittees promote.

How much have you seen paediatrics make an impact on the care for children and adolescents with mental health and intellectual and developmental disabilities?

Let me begin by recognising that specialist mental health services are the domain of mental health experts. However, general paediatricians are very actively involved in supporting families and providing the social, emotional and behavioural

aspects of healthcare care for children and young people. They work closely with other health professionals, such as general practitioners. If you look at the workload of a general paediatrician in the community, a very large proportion of their daily work is about those social, emotional, behavioural aspects of health, which is not always understood and acknowledged. However, that is a critical part of what they do. It seems to be something that parents as well as patients need and appreciate. We need to acknowledge and support this work and ensure an integrated relationship with the specialist aspects of mental health expertise so there is a continuum and we don't have two different silos working separately.

Are you IT orientated? Do you have a web-link you would recommend?

One website I have been particularly impressed with recently is www.raisingchildren.net.au. There is now a project lead by Professor David Bennett along with the NSW Kids and Families: Youth Health and Wellbeing team to expand the adolescent and young person aspects of parenting information on this website. The traditional focus of the website and of the Raising Children network has been on parenting of younger children.

Do you have a current project you are working on?

I am working on lots of projects as part of the role I have in seeking to coordinate services across the state. One is a project looking at maximising access to surgical services for children: the right services, the right place, the right time. This would allow the children's hospitals to do the specialist things that only they can do with the other hospitals being supported in doing operations that are not so specialised and that can be done closer to home. This is a tiered approach with appropriate access to services as close to home as possible and referral to the children's hospitals for things that need to go there.

Do you have a book you could recommend?

I don't really have time to read much fiction, mainly papers and reports. However the most recent book I read, while I was travelling on conference leave, was *A tale of two cities*- the old classic. It is brilliant literature but thoroughly depressing!



Celebrating the launch of DisabilityCare Australia

DisabilityCare Australia, the national disability insurance scheme, has now been launched in four launch sites: in the Hunter area in New South Wales, Geelong and the Barwon area in Victoria, in South Australia for children and in Tasmania for young people.

More than 26,000 people with a disability, their families and carers will benefit from the first stage of DisabilityCare Australia, which will be gradually implemented over the next few years to make sure people can transition into the scheme smoothly.

By 2019 around 460,000 Australians with significant and permanent disability will be supported by DisabilityCare Australia.

To find out more about DisabilityCare Australia, including the details of the launch sites, go to www.disabilitycareaustralia.gov.au.

Disability support services: services provided under the National Disability Agreement 2011-12. AIHW Bulletin: 2013, July, 118

Many people with disability are able to live independently and participate in society without assistance, or with the help of informal carers. However, others require formal specialist disability services to study, work, interact with the community or carry out everyday activities. This bulletin presents data collected in the Disability Services National Minimum Data Set (DS NMDS) on the number and

types of disability support services provided under the National Disability Agreement (NDA), including community support (received by 43% of service users), employment (42%), community access (20%), accommodation support (13%) and respite (12%). This information is important as the disability policy and service delivery environment continues to evolve, for example, with the introduction of DisabilityCare Australia (formerly the National Disability Insurance Scheme). http://apo.org.au/sites/default/files/docs/AIHW_DisabilitySupportServicesServicesProvidedUnderTheNationalDisabilityAgreement2011-12_July2013.pdf

UNICEF – State of the World’s Children report 2013: Children with Disabilities

UNICEF launched the 2103 edition of its flagship publication, *State of the World’s Children* that will focus on children with disabilities. The report covers children with disabilities in a varying worldwide landscape: how do they fare at home, in school, or at health care centres? What happens to children with disabilities in emergencies or conflict? How do these situations fluctuate around the world? The Report argues for inclusive and equitable approaches in such areas as early childhood development, education, health, nutrition, humanitarian response and protection. Based on documented experience and examples, the report will recommend ways in which Governments, the private sector, international donors and agencies, and other stakeholders can help advance this agenda. The report also gives a voice to children to encourage their position as

architects and agents of change in their towns, villages and cities, regardless of ability. To this end, in addition to the main narrative and expert technical panels, the report features perspectives, or personal essays, by policy makers, parents, care providers, celebrities and role models with disabilities and, most significantly, young people with disabilities that have accomplished personal or professional goals or are striving to do so. The hope is that report will foster greater attention on these children’s global needs and remarkable potential. <http://www.unicef.org/sowc/>

Fetal Alcohol Forum (Issue 9)

June 2013 issue of the fetal alcohol forum (Issue 9) with the latest research and articles. <http://www.chimat.org.uk/resource/view.aspx?RID=163879&src=LD>

BBC: SAP in autism recruitment drive

German software company SAP says it hopes to recruit hundreds of people with autism, saying they have a unique talent for information technology. <http://www.bbc.co.uk/news/business-22621829>

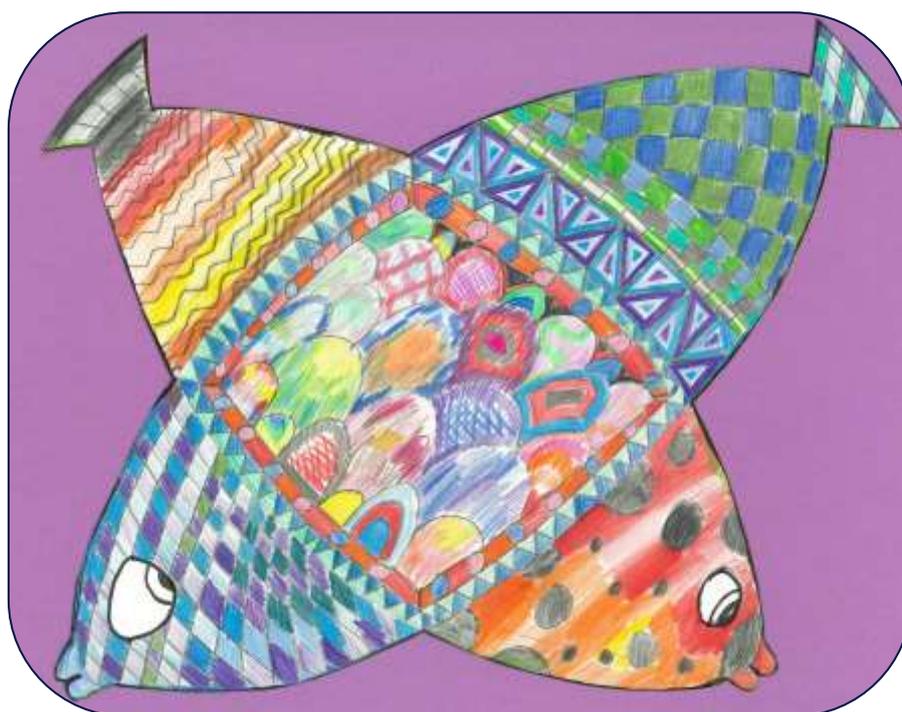
WHO: 66th World Health Assembly adopts resolution calling for better health care for people with disabilities

The 66th World Health Assembly on 22nd May 2013 has adopted a resolution recalling the Convention on the Rights of Persons with Disabilities and endorsing the recommendations of the 2011 “World report on disability”. The resolution urges Member States to implement as States Parties the Convention; develop national action plans; and improve data collection. Member States are encouraged to ensure that all mainstream health services are inclusive of people with disabilities; provide more support to informal caregivers; and ensure that people with disabilities have access to services that help them acquire or restore skills and functional abilities as early as possible. http://www.who.int/disabilities/media/news/2013/28_05/en/index.html

NSW Parliament Autism Spectrum Disorder Briefing Paper No 5/2013

The growing number of children diagnosed with Autism Spectrum Disorder (ASD) is an issue of concern both in Australia and overseas. More detailed concerns have been outlined in recent parliamentary debates. Lenny Roth from the New South Wales Parliamentary Research Service has created this 40 page document.

[http://www.parliament.nsw.gov.au/prod/parliament/publications.nsf/0/B2142391F94516FECA257B78001FB961/\\$File/Autism%20Spectrum%20Briefing%20Paper%205%202013.pdf](http://www.parliament.nsw.gov.au/prod/parliament/publications.nsf/0/B2142391F94516FECA257B78001FB961/$File/Autism%20Spectrum%20Briefing%20Paper%205%202013.pdf)



Dyke, P., Bourke, J., Llewellyn, G. and Leonard, H. (2013) **The experiences of mothers of young adults with an intellectual disability transitioning from secondary school to adult life** in *Journal of Intellectual and Developmental Disability* June 2013, Vol. 38, No. 2, Pages 149-162 The transition from school to adulthood for young adults with an intellectual disability involves movement from a generally secure and supported school environment to an emerging adult life that may be characterised by a wide variation in adoption of adult roles related to employment, independent living, friendships, and day activities. This Australian study investigated the perspectives of 18 mothers of young adults with either Down syndrome or Rett syndrome through qualitative semi-structured interviews. The International Classification of Functioning, Disability and Health (ICF) framework was used as a conceptual basis. <http://informahealthcare.com/doi/abs/10.3109/13668250.2013.789099>

Kasari, C. and Smith, T. (2013) **Interventions in schools for children with autism spectrum disorder: Methods and recommendations** in *Autism* July 2013 17 (4). Although researchers have identified many promising teaching strategies and intervention programs for children with autism spectrum disorder, research on implementation of these interventions in school settings has lagged. Barriers to implementation include incompletely developed interventions, limited evidence of their utility in promoting long-term and meaningful change, and poor fit with school environments. To overcome these barriers, interventions need to be detailed in manuals that identify key components yet allow for flexibility, and studies need to evaluate long-term, real-life outcomes. Innovative research strategies also may be important, particularly carrying out research on new interventions in school settings from the outset, conducting partial effectiveness trials in which study personnel administer interventions in school settings, using community-partnered participatory research approaches, and redesigning interventions in a modular format. USA article. <http://aut.sagepub.com/content/17/3/254.abstract>

Calder, L., Hill, V., and Pellicano, E. (2013) **'Sometimes I want to play by myself': Understanding what friendship means to children with autism in mainstream primary schools** in *Autism* July 2013 17 (4). According to the authors in the UK, research has shown that friendship impacts the overall experience of mainstream school for autistic children. Using a unique combination of quantitative, qualitative and social network methods, they investigated the extent and nature of autistic children's friendships from their perspective and from those of their mothers, teachers and classroom peers. <http://aut.sagepub.com/content/17/3/296.abstract>

Bauminger-Zviely, I., Eden, S., Zancanaro, M., Weiss, P.L., and Gal, E. (2013) **Increasing social engagement in children with high-functioning autism spectrum disorder using collaborative technologies in the school environment** in *Autism* July 2013 17 (4). This Israeli study examined the effectiveness of a school-based, collaborative technology intervention combined with cognitive behavioural therapy to teach the concepts of social collaboration and social conversation to children with high-functioning autism spectrum disorders as well as to enhance their actual social engagement behaviours (collaboration and social conversation) with peers. <http://aut.sagepub.com/content/17/3/317.abstract>

Muchetti, C.A. (2013) **Adapted shared reading at school for minimally verbal students with autism** in *Autism* July 2013 17 (4). Almost nothing is known about the capacity of minimally verbal students with autism to develop literacy skills. Shared reading is a regular practice in early education settings and is widely thought to encourage language and literacy development. There is some evidence that children with severe disabilities can be engaged in adapted shared reading activities. This current USA study examines the impact of teacher-led adapted shared reading activities on engagement and story comprehension in minimally verbal 5–6-year-old children with autism using a multiple baseline/alternating treatment design. Four students and three teachers participated. <http://aut.sagepub.com/content/17/3/358.abstract>

Neece, C.L., Baker, B.L. and Lee, S.S. (2013) **ADHD among adolescents with intellectual disabilities: Pre-pathway influences** *Research in Developmental Disabilities* Volume 34, Issue 7, July 2013, Pages 2268–2279 Children and adolescents with intellectual disabilities (ID) are at heightened risk for developing ADHD. However, the validity of ADHD as a diagnosis for youth with ID remains controversial. To advance research on validity, the present USA study examined the hypothesized precursors to ADHD in typically developing adolescents (TD) and adolescents with ID, specifically with regard to family history of ADHD, molecular genetics, and neuropsychological functioning. <http://www.sciencedirect.com/science/article/pii/S0891422213000930>

World autism awareness day 2013: a special virtual issue In recognition of World Autism Awareness Day 2013 (2nd April), publisher Wiley has assembled a collection of scholarly and professional research on autism. It comprises journal articles and book chapters from across relevant subject areas for researchers, professional and parents. Subject areas covered include education, intellectual disability, genetics, neuroscience, philosophy, psychiatry and psychology. <http://au.wiley.com/WileyCDA/Section/id-816279.html>

Courtesy of the UK Learning Disabilities and CAMHS eBulletin. <http://www.chimat.org.uk/>

Free training in intellectual disability and mental health

Would you like to gain knowledge, skills and confidence to improve the mental health care of people with an intellectual disability?

People with an intellectual disability have a higher rate of mental disorders than the general population, but have less access to mental health care.

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Topics include:

- Introduction to Intellectual Disability
- Living with Intellectual Disability
- Changing Perspectives of Intellectual Disability
- Introduction to Mental Disorders in Intellectual Disability
- Communication
- Assessment of Mental Disorders in Intellectual Disability
- Management of Mental Disorders in Intellectual Disability

For more information:

Email: idhealtheducation@unsw.edu.au

Website: www.idhealtheducation.edu.au



St Andrew's College Children's Camp



In December 2013, St Andrew's College will host the Sony Foundation St Andrew's College Children's Camp for children with physical and intellectual disabilities.

The Camp allows the children to experience a great range of activities such as swimming, arts and craft, a trip to the zoo, a jumping castle, visits from a fire truck and Santa! The children have a fantastic opportunity to meet new friends and gain a sense of independence.

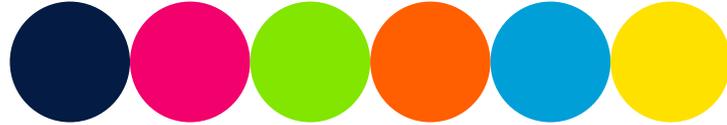
Only 16 places are available for children aged between 6-15 years. Applications close 15/11/13 but prompt applications are encouraged.

The organisers are looking for Volunteer Nurses who would be available to fill these shifts. Main duties of the volunteer nurses include: Administration of medication, supervision of the children, assistance in the unlikely event of an emergency.

For further information:

info@saccc.org.au

www.saccc.org.au/



Intellectual Disability:

Nursing patients with an intellectual disability 17-18 September 2013
Australian College of Nursing, Burwood NSW CPD hours: 14
studentservices@acn.edu.au
www.acn.edu.au

PANDDA 24th Conference, 16th -17th October 2013. Professional Association of Nurses in Developmental Disabilities Australia. Novotel Parramatta NSW 2150 www.pandda.net.au

48th Annual Australasian Society for Intellectual Disability (ASID) Conference, Sydney 6th- 8th November 2013. "Our Time" After so many years of advocacy, we celebrate the meaningful presence of people with intellectual disability on the main stage, alongside families and paid professionals from all the industry sectors.
<https://www.etchouches.com/ehome/ASID2013>

Autism Spectrum Disorder:

FREE two day workshop and information sessions for PARENTS/ CARERS of school age students on the autism spectrum by Positive Partnerships Hornsby 10th and 11th September 2013. Online registrations preferred: please go to the website www.positivepartnerships.com.au.

Secret Agent Society (SAS) Training for practioners in Sydney, 16-17 September 2013. An emotion regulation and social skills program for 8 to 12-year-old children with social and emotional challenges. Visit <http://www.sst-institute.net/au/professionals/practitioner-training/> for more information.

Special Education:

Australian Association of Special Education (AASE) National Conference, 'The Door is Open' Repertoires of Practice. 30th September - 1st October at the Hilton Hotel Adelaide . www.gemsevents.com.au/aase2013.

Challenging Behaviour:

Toddler clinic workshops as an introduction to Parent Child Interaction Therapy Model by *Karitane* for children with challenging behaviours. 3rd September 2012. Carramar. \$175. Contact 9794 2348 or enquire-skcfc@sswahs.nsw.gov.au for more information. You can pay online at <http://karitane.com.au/ProfessionalsEventsRegistration.php>

2014 Conferences:

Helping Families Change Conference: presented by *Triple P International*. 19th- 21st February 2014. Park Royal Hotel Sydney visit www.helpingfamilieschange.org

Linking Up for Kids Conference hosted by **Children's Healthcare Australasia (CHA)** and the **Australian Research Alliance for Children and Youth (ARACY)** 14th and 15th April 2014, The Menzies Hotel Sydney. Building strong partnerships between health, hospital and education systems to enhance child and youth wellbeing - a vision for the future www.childwellbeing2014.net.au/

Mental Health:

2nd edition Mental Health First Aid Course. or family and carers from an Arabic background. 27th August and 3rd September 2013. Parramatta. A free 12 hour mental health first aid course for MHFA training www.mhfa.com.au call 02 8842 8289.

Metro North BIS Symposium: Mental Health & Intellectual Disability 'Untangling the knots and working together for better personal outcomes' 27 August 2013, Rosehill
Cost: \$50; free for parents and unpaid carers. Keynote speaker: Julian Trollor: Accessible mental health services for people with intellectual disability. Guest Speakers: Gerhard Raftl: Mental Health from a trauma and attachment perspective; Jack Dikian: Prozac on the couch: Depression and anxiety in the era of wonder drugs ; Dr Bruce Chenoweth: Mental Health and Intellectual Disability in children; Dr Michael Fairley: Mental Health and Intellectual Disability in Adults
Plus Quick-fire Presentations.
Brought to you by the BISevents Team, a collaborative effort of Ageing, Disability and Home Care, Autism Spectrum Australia, Sunnyfield, Interaction Disability Services and Wesley Mission.

Registration forms available on our School-Link website:
<http://www.schoollink.chw.edu.au/>

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www.schoollink.chw.edu.au

Please forward this newsletter to other professionals interested in Mental Health and Intellectual Disability

the medicine cabinet: Quetiapine

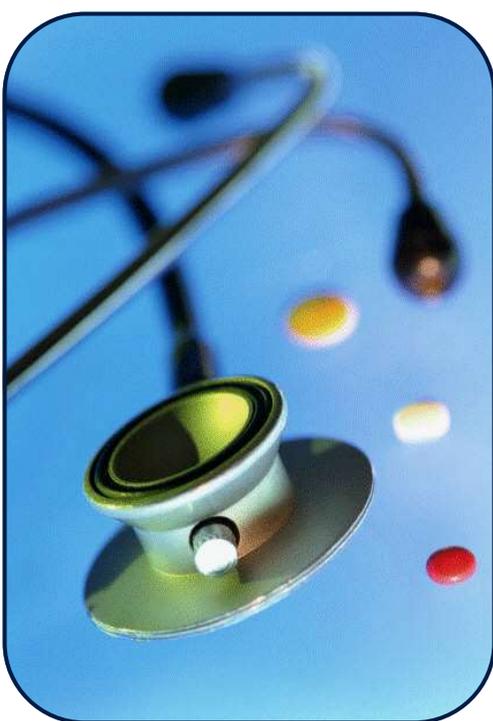
Quetiapine – a weak antipsychotic that is a great anxiolytic (anti-anxiety medication) and excellent for acute agitation

Kenneth Nunn
Senior Child Psychiatrist, and
Judy Longworth
Senior Clinical Pharmacist

Department of Psychological Medicine
The Children's Hospital at Westmead

What are we treating?

In psychiatry, when treating patients, medication is often used to promote general safety rather than specific treatment, relieve symptoms rather than cure the disease. This is even more true for child and adolescent mental health where diagnostic uncertainty is present even where the young person may be very ill impaired. Most medications have been validated against symptom counts, not simply whether they have, or do not have, a given diagnosis. Arousal, agitation, aggression, anguish, restlessness, out-of-control behaviour and self-harm, are often more important, acutely, than whether or not someone has a particular diagnostic syndrome. This leads to uses both *licensed* (ie what the parent drug company applied to the Therapeutic Goods Association (TGA) to be marketed for use) and *off-label* (ie all the other indications for which the drug might be used). We treat the young person first and the specific diagnosis second.



The importance of sleep in psychiatric disorder

One very important symptom is sleep disturbance. Sleep disturbance is often the first sign of an impending episode of illness or of relapse. Severe sleep disorder is such a common accompaniment of mental illness, especially acute mental illness, that “**sedation or no sedation?**” is a key part of any medication decision tree. Quetiapine is a sedating second generation antipsychotic. Although it is called an *anti-psychotic* it has a much wider spectrum of symptom relief. It may be used for psychosis, mood disorder, bipolar disorder, depression, PTSD or anxiety. It may also be used for aggression where there is a willingness to take oral medication. All of these conditions have increased, often extreme, physiological arousal and motor activation in common.

Dealing with old problems in a new way

Quetiapine is a clozapine /olanzapine (brand names Clozaril® / Zyprexa®) like medication that is a *dibenzothiazepine*. This means that it is a cousin medication of diazepam (Valium®), but stronger and less addictive. Quetiapine will reduce the *positive symptoms* of psychosis, such as hallucinations and delusions. It will improve the *cognitive symptoms* (poor concentration and planning) as well as *negative symptoms* (inability to relate in groups, difficulty talking about feelings, difficulty experiencing pleasure or finding interest, and loss of motivation). Quetiapine does this without causing the traditional problems that were associated with the original first generation antipsychotics that were in use 20-30 years ago. Old style, first generation antipsychotics, like chlorpromazine and haloperidol, caused Parkinson Disease-like symptoms that slowed people up in their thoughts, their movements and even in the expression of their feelings. Some of them would also cause the hormone prolactin to rise, which reduced libido and would sometimes cause fullness of breasts and milk production. It was sometimes a big cost to pay to stop the anguish and impairment of psychosis.

How long does it take to work?

Quetiapine immediate release preparations reach maximum plasma concentration around 1.5 hours after ingestion. Quetiapine generally has an estimated half-life (time taken time for the drug to lose half its level in the blood) of 6-7 hours. Quetiapine XR (extended release) peak at 5-6 hours. These times are adult times and in small studies to verify the times in adolescents they are slightly shorter times so dosing may need in some cases to be more frequent.

“Although it is called an *anti-psychotic* it has a much wider spectrum of symptom relief...”

What are the side effects of quetiapine?

The most common side effects are:-

- Sedation (short term)
- Postural hypotension (short term), a drop in blood pressure upon standing
- Dry mouth (medium term)
- Constipation (medium term)
- Weight gain (long term)
- High cholesterol, high triglycerides and high blood fats (all long term) are generally associated with weight gain and these lead to ongoing health issues such as diabetes that need to be monitored regularly (long term).
- Abuse potential (special setting side effect) – quetiapine has an emerging abuse and medication diversion (ie giving it to others) profile in forensic populations such as prisons and juvenile detention centres.

Quetiapine is extensively metabolised in the liver. While there is potential for drug interactions the vast majority of young people tolerate quetiapine well. They may be over sedated if put on the medicine regularly but this reduces rapidly after 3-5 days.

What happens if a patient overdoses on quetiapine?

In patients who regularly take quetiapine the lethal dose is far higher than those who have never taken the drug. Even so the tolerance for overdose is extremely high and few deaths have been recorded as a result of overdose. Toxic effects include sleepiness, unconsciousness, increased heart rate and low blood pressure.

What happens when the patient is pregnant, or breast feeding?

When used in pregnancy, quetiapine has a low rate of placental transfer but with use of medication during pregnancy and lactation the use needs to be weighed against the harm from the untreated mother. Currently there is an ongoing Australian psychotropic database that collects the records of mother and babies prescribed antipsychotics during pregnancy. This database can be accessed through Mothersafe 1800 647 848.

Conclusion

Quetiapine is a good sedative when a traditional benzodiazepine is to be avoided and a good acute treatment when physiological arousal and motor agitation must be lowered. Except for acute sedation, we generally avoid benzodiazepines (like diazepam: Valium®) in children and adolescents as they cause behavioural and emotional disinhibition and paradoxical over excitement in some. Quetiapine causes much fewer problems than traditional antipsychotics with Parkinson-like symptoms, but remains a metabolic challenge long term by causing weight gain. In general, if a medication sedates it puts on weight. For this reason we may switch from quetiapine as we move from acute to longterm medication management and if weight emerges as a problem. The extended release formulation offers once day dosing (or more subtle twice daily dosing) and potentially less daytime somnolence. Quetiapine generally requires a cooperative patient because intramuscular and intravenous formulations are not available. Its lack of sustained dopamine receptor blocking (so called D₂ occupancy) is thought by many clinicians to be the reason it is not as good at reducing longer term, or intractable, positive symptoms of psychosis as other newer antipsychotics.

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Practical information in relation to the public funding of quetiapine

Quetiapine was, and still is, marketed by Astra Zeneca and has recently come off patent in Australia. This means there are now generic equivalents available, which can mean the cost of the medication to the Australian government through claims via the PBS has also reduced. So instead of one brand name there are now 18 different brands of immediate release tablets. Extended release tablets (4-6 hours to work and continue to work for longer) are still patented to Astra Zeneca.

In Australia, quetiapine is reimbursed for treatment of schizophrenia and bipolar disorder, both as single therapy during the acute manic phase and maintenance and thus subsidised by Pharmaceutical Benefits Advisory Committee (PBAC). Quetiapine is licensed ie what is recorded on the product information and applied for through TGA is listed below

TGA Indications Bipolar disorder.

Children/ adolescents aged 10 to 17 years. Monotherapy treatment of acute mania associated with bipolar I disorder. Schizophrenia.

Adults and adolescents aged 13 to 17 years. Treatment of schizophrenia.

Specialist information for medical practitioners and pharmacists

Quetiapine is metabolized mostly by CYP 3A4 in the liver and this means it is much less likely to be affected by the commonly reduced enzyme activity of CYP 2D6 (ie poor or intermediate metabolizer status).

Quetiapine has stronger 5HT₂ receptor blocking capacity to D₂ blocking capacity. (5HT₂ : D₂ affinity ratio) than first generation antipsychotics. 5HT_{2A} antagonism leads to reduction in glutamate release, which in turn reduces mesolimbic dopamine release, thus reducing positive symptoms.

Partial blockade of 5HT_{1A} can increase dopamine release in the frontal cortex (so called mesocortical dopamine system), which could improve affective, cognitive and negative symptoms while also reducing the risk of the debilitating EPS and prolactin elevation. 5HT_{1A} agonism can also decrease glutamate release, which could indirectly reduce positive symptoms of psychosis.

As for adverse effects quetiapine as, already mentioned, has lower EPS (parkinsonism) tendency due to the agonism of 5HT_{1A} receptors. But quetiapine also has agonist effects on many other receptors, listed below:

- Alpha₁ adrenergic receptors - postural hypotension
- Alpha₂ adrenergic receptors – postural hypotension, sedation
- M₁ Muscarinic receptors – dry mouth, constipation
- Histaminergic receptors – weight gain, sedation
- 5HT_{2C} receptors – weight gain.

Compared to the other antipsychotics there are less extra-pyramidal side effects (EPS), meaning less muscle stiffness, Parkinson-like symptoms or tendency to **suffer from an oculogyric crisis (“the look ups”)**. **There is less prolactin elevation** and therefore less effect on libido and less galactorrhoea. Daytime somnolence, unwanted sedation and lethargy are all common. Sometimes this can be managed with dose adjustments (eg loading towards evening) as well as use of the XR. Steady state levels are reached within 48 hours on regular doses and over sedation usually attenuates after a further 48 hours, with histamine receptor desensitization.

Regular weight assessment can help as can some regular exercise. Rhinitis and nasal congestion and mild elevation of QTc have all been noted but with little consequence. XR formulation has a similar profile but the single daily dose may be associated with less daytime sedation. Cataracts, at much higher doses than used in humans, have been found in dogs. Tardive dyskinesia and neuroleptic malignant syndrome are thought to have occurred, although quetiapine is sometimes used to treat tardive dyskinesia, as is clozapine. There are limited studies and most are anecdotal. Tardive dyskinesia is much less frequent than typical or first-generation antipsychotics, such as haloperidol. Raised liver transaminases that return to normal with continued use occur in 6% of those on longer-term treatment.

National Roundtable Report

The National Roundtable on the Mental Health of People with Intellectual Disability: A Summary.

Assoc Professor David Dossetor

A first National Roundtable on the Mental Health of People with Intellectual Disability (PWID) was held in Canberra on 22.5.13 organised by the NSW Council of Intellectual Disability (CID) in partnership with the Department of Developmental Disability Neuropsychiatry University of NSW (3DN), Australian Association of Developmental Disability Medicine and the Queensland Centre for Intellectual & Developmental Disability (QCIDD), with the funding and support from Department of Health and Ageing. The meeting included a focused consultation with 95 recognised leaders in mental health and intellectual disability from consumer and advocacy representatives, health, mental health, disability, education and non-government organisations to develop 'a guide for providers' on 'accessible mental health services for people with intellectual disability', which will be shortly released for wider consultation.

The day was an extra-ordinary gathering, capturing the level of problems and of practical potential developments from significant leaders in the field, which received general recognition by the participants. This is not a minor problem with an estimated 56,000 people with intellectual disability and mental health problems (PWIDMH) in Australia. The day was grounded by the appalling and traumatic personalised experiences of consumers with intellectual disability and their carers, and their accounts of how the services systems failed to provide an understanding or diagnosis of their mental health problems, let alone effective treatment over many years (which may be published elsewhere). Rosemary Huxtable, Deputy Secretary Department of Health and Ageing, emphasised the importance of the National Disability Strategy. One key performance target is for PWID to be able to obtain the highest possible health and wellbeing throughout their lives, and be able to contribute to their community. This policy direction will require all health service providers to meet the needs of this special need population, including timely prevention and early intervention. Universal health reform must address PWID, their families and carers. There is a potential for further funding with the Roadmap for National Mental Health Reform. Professor Allan Fels the Chair of the National Mental Health Commission validated the consumer experiences as common, with poor access to mental health

care and frequent errors in diagnosis. This is in the context of a massively underfunded mental health system, and the broader context of this country's failure to provide an appropriate mental health service for the burden of health need. In the context of the National Disability Insurance Scheme (NDIS) now called DisabilityCare Australia, strategy to up-skill all services, with clear service pathways plus a focus on prevention and promotion of mental health provides a vision which has a capacity to enable all PWID to lead contributing lives and with potential to lower government budgets in disability and health.

“There is a need to recognise a national network of specialists in mental health and intellectual disability and training to back up mainstream services. ...”

Jim Simpson a lawyer from CID has been an articulate and compassionate lead figure in bringing this agenda to wider attention. He identified the components of challenge and the need for change:

1. mental health problems in PWID are difficult to diagnose, with communication problems, atypical presentations and the need to look at the underlying causes of challenging behaviour.
2. PWID have poor access to mental health services, and psychiatrists report self-perceived lack of training and poor quality of care in mainstream services. Thus far funding for the PWIDMH has not been adequately considered.
3. The mental health of PWID also needs to be considered in schools, general practice and paediatrics. All mental health services should provide equitable access, and one service indicator could be the **rate of the 'diagnostic cop out' of just 'behaviour problem' instead of careful assessment to recognise mental health problems and identify their treatment.**
4. There is a need to recognise a national network of specialists in mental health and intellectual disability and training to back up mainstream services. ACT has a viable model of a small multidisciplinary team of specialists in mental health and intellectual disability that provides both a community based service and supportive in-reach to mainstream mental health services and collaborative relationships with disability services.
5. There should be joint planning between mental health, education and disa-

bility services with clear pathways to service provision and early access to multidisciplinary teams, which is currently a rare experience.

6. Training is required in mental health of intellectual disability in all services.

7. Data is needed on the service provision specifically for those with intellectual disability.

8. There needs to be a focus on multiple disadvantage, including those in poverty, in the criminal justice system, from Indigenous backgrounds and from backgrounds of cultural and linguistic diversity.

9. The NDIS is required to provide appropriate supports, including behaviour support and behaviour therapy, but does not provide clinical mental health services. In April the Council of Australian Governments documented the requirement for all state and territories governments to have inclusive services, specifying inclusion of PWID. They are also obligated to improve interagency interactions with mental health systems as part of the national Roadmap for Mental Health Reform. The NDIS may not fund health and mental health services, but does create an opportunity for change of the health and wellbeing of PWIDMH. The NDIS launch sites will need to develop principles for world standard practices of managing NDIS packages. They must also establish partnerships with health and mental health services, as these may be the most readily changeable contributions to disability.

Currently specialist mental health services for PWID are driven by a few individuals and their vision needs to be ramped up to develop a concerted action in mental health to share a vision of a decent life of PWIDMH.

Prof Nick Lennox, President of the Australia Association for Developmental Disability Medicine and QCIDD has been researching on primary health care for PWID for 21 years. He started by saying that this country, by international standards, has a good primary health care system of equity of access and cost effectiveness. However a focus on the empowerment of PWID will still require system change. Research, including three randomised controlled trials shows that annual health assessments of PWID improve their health. Awareness of the Medicare item of annual health assessments needs to be improved, and reintroduction of the intellectual disability specific Medicare item would allow us to monitor general practice access for PWID. The annual health care assessment also improves relationships with and reduces fear of the health service for PWID. In his research,

general practitioners were extremely motivated to be involved in the health care of PWID, recognising their special responsibilities, and the benefits of continuity of care in general practice. Electronic health records will provide measurable benefit for the complex health issues of PWID. He advocates establishing a website of **'60 million health stories' from across the globe** to enable consumers and carers to learn from each other, because of the diversity of health and mental health problems for PWID.

Emeritus Professor Bruce Tonge Child Psychiatrist of Monash School of Psychology and Psychiatry reported on some findings from their 25 year longitudinal epidemiological study of the mental health problems of children and youth with intellectual study. Of people with intellectual disability, children and adolescents have 3-4x rates of serious mental health problems compared to mainstream young people, adults 2-3x and the elderly have 2x. The scale of the burden of their mental health problems is greater than that of schizophrenia. Yet less than 10% receive appropriate mental health services as their needs fall between the silos of disability and mental health. These mental health problems are a key barrier to their problems of social inclusion and participation. These problems start early and persist, therefore we need early intervention. These problems do not follow the same trajectories as mainstream mental health problems because they are substantially biologically driven, as illustrated by our knowledge of behavioural phenotypes. Parents need education of these developmental problems and parenting skills as these behaviours **don't respond to intuitive skills. Mostly the causes, such as genetic factors, can't be prevented.** Although geography and socio economic factors are important, these problems are escalated by disadvantage such as Indigenous background and are more severe where this is remote. These are associated with additional health difficulties for example epilepsy but this is only where epilepsy is not treated or controlled which is common in remote communities.

PWIDMH are frequently excluded from school, post school options, and employment and where they are employed are **subject to injury and worker's compensation.** Their mental health problems place an inordinate burden on their families. The services are poorly coordinated. Early intervention is required for all children with developmental disorders, not just for ASD! The evidence base shows this should start with parent education followed with teaching special parenting skills, and additional support for transi-



tions: into school and high school and then into post school placements. We need significant up-skilling of the workforce for PWIDMH, including psychiatrists, psychologists and developmental paediatricians and all front line staff that deal with PWID.

A/Prof Julian Trollor, Chair of Intellectual Disability Mental Health, 3DN, funded by Ageing Disability and Home Care NSW Family and Community Services, **presented on his department's initiatives: they aim to build workforce capacity with an on-line educational resource for mental health workers; this includes a survey of mental health staff attitudes and competencies. Since training initiatives aren't coordinated in this country, a national approach is required and the establishment of a virtual network of mental health workers with a special interest in intellectual disability.** They are looking at a data linkage study between disability and mental health services to build the evidence on access, inclusion and outcomes of PWID in mental health services. If a human rights foundation provides the right of access to mainstream mental health services, then data will drive the reform.

Maria Tomasic, President of the Royal Australian and New Zealand College of Psychiatry (RANZCP) emphasised the forensic mental health issues: PWID and mental health problems are over-represented in those that commit offences, and also come from socio economic disadvantage, have communication difficulties, are highly suggestible, more likely to be caught, and also more likely to be victims of crime. Intellectual disability,

mental health problems and involvement in the criminal justice system is the triple disability: they are not prioritized, not likely to access appropriate treatment, more likely to be imprisoned and less likely to get remand. They need specific treatments and rehabilitation which needs to be culturally sensitive and involve mainstream mental health services. RANZCP has thus far not included PWID because of the service divide created by the social model of disability services. We have relied on British graduates to bring the specialist psychiatric skills to these shores. In 2011 a college special interest group for PWID was established and the college has introduced a new competency based fellowship that will require all psychiatrists to have training in ID. The college plans that the special interest group should progress to subspecialty status, with the expansion of subspecialist research and services. Developments will depend on funding, but the mainstream services already have responsibility to demonstrate that they provide for this population. The Federal funding through the Health Education Training Institute for Specialist Training Positions in priority areas is ripe for use for developing services for PWID. Initiatives for PWID are overdue in RANZCP and it is the responsibility of the college to meet the needs of community and advocate for needs of PWID. Eddie Bartnik is the first of the Mental Health Commissioners and has been working in Western Australia for two years. He aims to develop community psychiatric services with a transfer of funding from the hospital based services with a greater emphasis on person centred approach, optimism and recovery. Collaboration between

National Roundtable Report continued

disability and mental health services needs to be a two way process with shared vision and values and mutual accountability. One problem is that mental health is not a single system, but responses vary according to service and hospitals. The psychiatrist carries so much responsibility for making the decision to admit or discharge, without alternatives of where to discharge patients to. There is no standardisation of admission and discharge processes. All this is underpinned by a mental health service that only has 50% of required funding to function adequately. There is a need for greater involvement by families and carers. With 100 different priorities in such a system, where do you start? The health system priorities are currently driven by the four hour limit rule of admission to an emergency service, waiting lists for surgery and Activity Based Funding, so it is difficult to get PWIDMH on a district health service agenda. There is data confirming that intellectual disability is a significant cost driver to health care, both for in and out patients. If Activity Based Funding is not going to ignore the needs of PWID, then it will need refining with an additional cost fraction for ID as happens for rural and remote and indigeneity. How do PWIDMH with complex needs, whose presentations are getting younger, get a service? How do you scale up the specialist skills of mental health and intellectual disability? It is important to start with those who get stuck in psychiatric hospital for 10 years and bring the best available expertise in. This will involve psychiatric leadership, helping one person at a time!

‘The guide for providers of accessible mental health services for PWID’ is designed to be suitable for general practice, community health, public and private hospitals, all age mental health services including community, outpatient and inpatient services, criminal justice services, drug and alcohol services and specialist intellectual disability health and mental health services. The principles of service provision focused on: rights, inclusion, person-centred approach, promoting independence, and recovery-orientated practice. The key components of accessible mental health services for PWID included: access to mainstream services, access to specialist ID mental health services, identification of care pathways, training and education for practitioners, interagency collaboration and partnerships, data collection and evaluation and inclusion in policy development. Break out groups specially considered primary care and general health services, public and pri-

vate mental health services, prevention, promotion and early intervention across the life span, with particular attention to practical steps in the education system to meet the needs of PWID. These principles were broadly endorsed. There is still time for fine tuning and wider consultation with a range of important stakeholders. The draft will be made publically available.

The day was summed up by further key lead figures: Liz Marles President of RACGP said that PWID are vulnerable and have additional access problems if they are Indigenous or come from a culturally and linguistically diverse background. GPs need to develop long-term relationships and direct access to and coordinate different resources. Medicare locals with their additional allied health staff may be able facilitate this coordination. The to-do list requires a network of professionals with an interest in ID, increased resources, better education through medical media and promoting the ID Medicare Annual Health Assessment, including social and emotional wellbeing.

“A national agenda was set for a new direction, with a need to work at how progress can be implemented locally.”

Keith McVilly of the Australian Psychological Society and Principal Research Fellow of Deakin University reiterated the need for a lifespan perspective, from early intervention and education initiatives, to multidisciplinary team collaboration with joint policy statements, from general practice, nursing, psychology, allied health and psychiatry. Progress will be driven by evidence based practice. Behaviour Support is rocket science, in that it needs to be allowed to fly to make a difference. Data on process and outcomes should drive finance and human resource investment.

Frank Quinlan of the Mental Health Council of Australia questioned how do we develop **local systems of PWIDMH when we ‘don’t have a mental health system’? There are a raft of services and programs that only relate to each other sometimes. The mental health system is tremendously overloaded and only one in three people getting the access to the expertise they need. There will be improved efficiencies, but mental health will need to attract new resources through advocacy, politics and evidence. Service integration will only hap-**

pen if we get the connection between policy, funding and service integration. So many PWID report that they got better *despite* the mental health system. Ultimately it depends on consumers determining what services they need. Western Australia has the best data linkage on PWID. There are plenty of examples of good practice. We need to use optimal case studies to drive guidelines and look for highlights and expertise in the system. Action will arise from a combination of aspiration and cause for complaint. This is the moment to take initiatives forward for PWIDMH.

In conclusion, the historic achievement of the NDIS has brought the needs of PWID **into the national conscience. The ‘guide for service providers’ will give new direction for benchmarking the standards of health and mental health services for PWIDMH. The important contribution of individuals who have specialist MH&ID skills was recognised, who need to develop a stronger voice with the establishment of a national multidisciplinary professional network for specialists in MH&ID. The importance of cross agency collaboration was emphasised and the need to develop specialist approaches to prevention, promotion, and the special role of schools and education. Specialist mental health services for PWID will need to be developed. In addition, every mental health service needs to identify clinicians from within their workforce with a special interest in PWID. All mainstream mental health staff will need additional training in MH&ID.**

This was a landmark event in the history of services for PWIDMH. A number of important challenges were voiced and pathways forward proposed, with the expectation for stepwise continuing improvements in the services for PWID in the next five years. These will be reviewed and reported on by consumer advocacy groups and should be included in the regular report cards of Federal and State Mental Health Commissioners. PWIDMH as a marginalised and disadvantaged minority special need population can no longer be ignored as a priority area for mental health reform and service development. A national agenda was set for a new direction, with a need to work at how progress can be implemented locally.

Further background reading about the roundtable is available at the NSW CID website: <http://www.nswcid.org.au/images/communique.pdf>

TRANSITION FOR CARERS FORUM

Transition is the period when a child moves from adolescence to adulthood. It is a complicated process for children with chronic health conditions, but is far more complex for those who have additional issues such as an intellectual disability, cognitive impairment, autism or brain injury.

As a part of our Carers Week activities, The Carer Support Program at the Children's Hospital at Westmead invites parents and carers to attend the Transition for Carers forum and expo.

REGISTRATION IS FREE. Morning Tea and lunch provided.

WHO: This forum is for parents & carers of young people aged 14 – 18 years who have a chronic health condition & who, because of a disability, will have difficulty managing their own care as adults.

WHEN: 18th October 2013, 9.15am - 2.30pm

WHERE: The Kids Research Building
The Children's Hospital at Westmead.
Cnr Hawkesbury Rd and Hainsworth St,
Westmead.

Carer Support Program
the children's hospital at Westmead



Topics include:

- Navigating the adult Health system
- Consent and decision making
- Employment and post-school programs
- Panel discussion with carers who have transitioned
- Expo of services and organisations providing support after transitioning

REGISTRATION IS ESSENTIAL

To register call 9845 3590.
Email carersupport@chw.edu.au
Registrations close on 11/10/2013.
Places are limited.

NOTE: Professionals in this field may register, but will only be offered a place if all available places have not been filled by parents and carers at close of Registration. Registration is on first come basis.

“Kids Quit” Smoking Cessation Training ; Talking to adolescents, parents or carers about smoking

In 2008, The Children's Hospital at Westmead (CHW) launched an e-learning package on Smoking Cessation Brief Interventions: Application to Parents, Carers and Adolescents. This package was created by the Departments of Adolescent and Respiratory Medicine, Kids Health, Pharmacy and the Education Centre and is for anyone that works with adolescents.

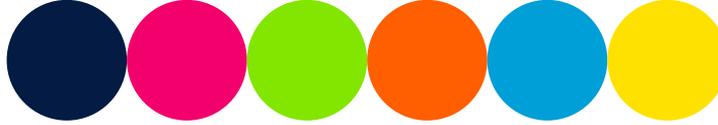
Education to adolescents, parents and carers regarding improving their health by smoking cessation is everyone's responsibility. The development of the e-learning package aims to increase confidence and knowledge in providing simple advice and assistance to those who smoke. There is evidence that smoking cessation advice to those who smoke is effective in encouraging smoking cessation.

The two-hour workshop involves completing a pre and post questionnaire, e-learning program and a follow up interac-

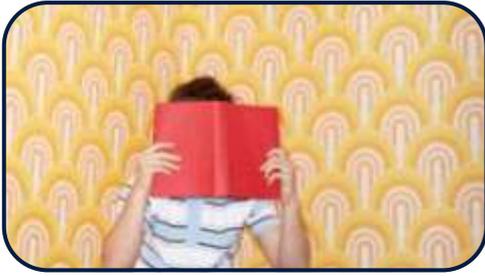
tive tutorial on frequently asked questions and discussion points. The tutorial also includes a KIDSQUIT Smoking Cessation Resource Folder, a copy of e-learning Smoking Cessation Training CD and Resource USB left with the team to enable further peer training for other members of staff.

To express your interest in the “Kids Quit: Smoking Cessation Brief Interventions” workshops, please contact Erin Simmonds on (02) 9845 3564 or email Erin.Simmonds@health.nsw.gov.au Further information is available at <http://kidshealth.schn.health.nsw.gov.au/projects/smoking/kids-quit-smoking-cessation-brief-interventions>





reviews...



Book Review:

A Clinical handbook on Childhood Development Paediatrics– Sandra Johnson
Approximate retail: \$70

This is a helpful handbook, aimed at paediatric trainees but a useful overview for all child clinicians. As well as the text version, access is given to a searchable on-line version, which may be more accessible for parents interested in understanding developmental disorders. Its content is valuable for an appreciation of concepts and measures of development, and what constitutes significant delay. The content illustrates why this area is the middle ground between paediatrics and child psychiatry and therefore of interest to trainees and practitioners in both. Chapters include normal development, developmental assessment, motor development and coordination, hearing and vision loss, ASD, specific learning disorders, language disorders, and ADHD. A useful chapter looks at behaviour difficulties, and when they can be considered significant enough to qualify as a child psychiatric disorder. There are also chapters on school refusal and mood disorders in children and adolescents, cerebral palsy, intellectual disability, child abuse and neglect and legal issues. San-

dra wrote most of the content and she is well qualified, having practiced in this area in both the public health system and as a private practitioner. She was ably assisted by some respected NSW colleagues in Developmental Paediatrics, Neurology, Brain Rehabilitation and Child Psychiatry and reviewed by some international academics. It is sound and sensible in content, written by experienced clinicians with clinical cameos but with good selective referencing including useful websites for further resources in assessment and intervention. It is both readable and a useful resource. The small print means that it conveys a lot of information for the size of the book written based on the research evidence. When one considers each chapter can be considered a subspecialty of paediatrics, it has to be seen as a concise overview. Although the chapter on legal issues is not particularly germane to developmental paediatrics, I found it also a helpful summary of the medical interface with the legal system. This book is an up to date summary and sets the standard of what every paediatrician or child psychiatrist should know about developmental paediatrics. It is also worth noting that Sandra has now just released a sequel called **“Your Child’s Development”** written for parents but suitable for other non-medical professionals such as teachers and carers available as a paperback (\$22) or for kindle (\$16), (http://www.amazon.com/Childs-Development-Sandra-Lucille-Johnson/dp/0987548247/ref=tmm_pap_title_0#_).



Organisation Review:

Righteous Pups Australia

www.righteouspups.org.au

Righteous Pups Australia is a not for profit organisation with a mission to raise, socialise and train Autism Assistance Dogs to do a variety of practical tasks for Children with Autism Spectrum Disorders and their families. The impact each dog makes on the life of their recipient is priceless, giving recipients a greater level of independence, self-esteem and an overall improvement in psychological well-being and quality of life.

They also train Therapy dogs who, visit and interact with older persons, the infirmed, persons with disabilities and the socially isolated within the community. This includes working with academically and/or socially challenged high school students through the S.W.A.T. (Specifically Working with At-risk Teens) program. There has been a positive impact on those with anger and depression related issues.

Have you been to a conference, read a book or visited a website that you loved?
Send us an overview to:
schoollink@chw.edu.au

The beautiful artworks in this newsletter are taken from the participants of the **Operation Art project** at the Children’s Hospital at Westmead. You can find out more at http://www.pau.nsw.edu.au/Visual_arts/Operation_Art/index.htm

A sincere thankyou to all children and adults involved in the production of these artworks and this newsletter. Remember; **Think Kids**

contact us...

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